

**NEVADA STATE WELFARE DIVISION
PUBLIC WORKSHOP ON PARENTAL RESPONSIBILITY**

The Public Workshop on Parental Responsibility was brought to order by Nancy K. Ford, Welfare Administrator, at 9:00 a.m. on Friday, August 13, 2004. This meeting was video-conferenced between the Legislature Building, 401 South Carson Street, Room 2135, Carson City, Nevada and the Grant Sawyer Building, 555 East Washington Avenue, Room 4412, Las Vegas, Nevada.

PANEL

Nancy Ford, Welfare Division
John Liveratti, Division of Health Care Financing & Policy
Mary Liveratti, Department of Human Resources
David Luke, Mental Health and Disability Services

STAFF PRESENT

Sharon Vail, Welfare Division
Janice Stenson, Welfare Division
Glenda Perryman, Welfare Division
Audrey Vanlier, Welfare Division
Tammy Dean, Welfare Division
Gwen Stewart, Welfare Division
Louise Bush, Welfare Division
Jeanette Gogna, Welfare Division
Miki Primus, Welfare Division
Amanda Aseph, Welfare Division
Laurie Buck, Deputy Attorney General
Palisa Pendleton, Division of Health Care Financing & Policy
Kat Parker, R.N., Division of Health Care Financing & Policy
Ceci Benitez, Division of Child & Family Services
Brenda Kastelitz, Division of Child & Family Services
Joe Palmer, Division of Child & Family Services
Tammy Ritter, Division of Health Care Financing & Policy
Janet Serial, Division of Health Care Financing & Policy
Tina Gerber-Winn, Division of Health Care Financing & Policy

GUESTS PRESENT

d'Arcy Bostic, Parent
Patsy Prothro, Nevada Disability Advocacy & Law Center

Anita C. Morrimer, Concerned Citizen
Jany Robinson, NEIS
Angela Ybarra, UMC
Kathy Raney, NEIS
Karen Davis, Parent
Mary Bolduc, Parent
Susan Morris, Parent
Carol Matrone, Parent
Michele Gibbs, Parent
Michael Diamond, NNCIL
Robert Desruisseaux, NNCIL
Lora Olvera, Rural Regional Center
Suzanne Hurley, Concerned Citizen
Grant P. Ulmer, Concerned Citizen
Danielle Johnsen, EUCH
Jon Sasser, Washoe Legal Services
Lisa Erqueaga, Northern Nevada Center for Independent Living
Bet Livercome, IVCH
Chritiane Dumas, Parent
Fay Boise, Sierra Regional Center
Eric Dewitt-Smith, Sierra Regional Center

Ms. Ford opened the public workshop at 9:00 a.m. She explained this public hearing is being video-conferenced between Carson City and Las Vegas and is being broadcast on the Internet. The public workshop has been posted in accordance with the open meeting law. Ms. Ford explained this public workshop is being held to garner input on the Welfare Division's policy of parental financial responsibility. This subject affects other agencies such as the Division of Health Care Financing and Policy, Mental Health and Disability Services and the Department of Human Resources.

I. PARENTAL FINANCIAL RESPONSIBILITY FOR SERVICES PROVIDED TO DISABLED CHILDREN:

Ms. Ford stated she received letters and information from Elizabeth Webb-Beyer, Julia Jones and Lynn Bidley of the Nevada Disability Advocacy and Law Center. These documents have been made a part of the permanent meeting record and may be read into the record, time permitting.

The panel of Dave Luke, Mental Health and Developmental Services; Laurie Buck, Attorney General's Office; Mary Liveratti, Department of Human Resources and, John Liveratti, Division of Health Care Financing and Policy, introduced

themselves. Ms. Ford had hoped to have a representative from the Health Division in attendance, however they were unavailable.

She explained the workshop is about parental financial responsibility for children on the different medical assistance programs. When eligibility for Medicaid is determined for disabled children, the parental income does not count toward the child's eligibility. There are statutes stating parents of minor children are responsible for public assistance provided, which is how the parental responsibility program was created. Parents with a substantial income are required to contribute toward their child's care, rather than the taxpayer paying 100% of their care. This issue has not been addressed since it was adopted about 10 years ago and Ms. Ford would like to receive information from the public about any adjustments, if any, that should be made to the program. She emphasized there will be no changes made at this meeting. If changes are to be made to the program, a public hearing must be held in order to adopt the changes. Those interested in receiving public meeting notices need to leave their address with the secretary.

Suzanne Hurley is concerned about the worksheet as her child receives Medicaid assistance through the Katie Beckett Program free of charge and has not been asked to pay anything. She stated she is confused about the worksheet handout as she was told if her paperwork was filled out incorrectly she would have to pay for assistance. Ms. Ford clarified she may not have a financial responsibility to continue her child's Medicaid, depending on circumstances.

She reviewed the worksheet handout and explained concerns were expressed by many people about how much the parental financial responsibility is for these Medicaid programs. Staff decided to have a workshop in an open forum to discuss the concerns and possible adjustments. Potential adjustments identified so far have a direct financial impact on the Division of Health Care Financing and Policy (DHCFP), the division which administers the Medicaid Program, as the payments for parental financial responsibility go to DHCFP to help offset costs incurred. These are increasing the family deduction percentage of poverty from 200% of the federal poverty level and increasing the amount of the child care deduction.

Grant Ulmer asked if the health insurance premium deduction is for the disabled child or the household as a whole because most people are on the programs because they cannot get their children on a regular insurance policy at any cost. Ms. Ford explained this amount is the premium paid for the entire family and said the parental responsibility amount is less if insurance is not available to the child than if the family elects not to purchase a policy available to them. She said the idea is to help the disabled child get insurance, not hurt the family financially. These Medicaid programs are tax-payer funded and the division is

trying to ascertain a reasonable amount for the family to contribute back to the program.

d'Arcy Bostic asked if children over 18 are part of the family unit for eligibility. Janice Stenson said if the children over 18 reside in the home they count in the family unit and if they are out of the home, even living on a college campus, they do not count as part of the family unit. Ms. Bostic asked if the deduction for an insurance premium deduction would be divided and the monthly premium used as the deduction. Ms. Ford replied the premium amount is not pro-rated, it is just deducted from the parental responsibility obligation amount. She said the division encourages families to buy health insurance if they can.

Suzanne Hurley is concerned about the different deductions for medical bills not allowable as a deduction for the parental responsibility payment amount. She cited an example of her son needing medical assistance while out of state and her having to pay the bill because Medicaid would not pay it.

Ms. Ford asked the attendees if they feel the parental responsibility amounts they are assessed is unreasonably high.

Carol Matrone has a child on the Katie Beckett program and commented the typical respite costs at \$12 per hour which underrates the child care deduction amount of \$150. She will take the worksheet home to review it to see how it will effect her family and would like the opportunity to comment on it at a future meeting. Ms. Ford stated she is always open to public comments and concerns. If there are additional comments or concerns after this workshop, she encouraged people to submit their comments to her. The next step, if anything is to be changed, is a public hearing and comments will also be taken then. Ms. Matrone commented there have been numerous changes to the Medicaid system in recent years and different preventative procedures are not being covered. She wondered if these changes will result with more children in institutional care, which is more expensive than the current program. This is a fiscal issue, which must be addressed before it adversely affects the families who need these programs.

Ms. Ford stated the parental responsibility program is a Welfare Division program, however it does affect other agencies. This is why the representatives from other state agencies are in attendance. She explained the Welfare Division does eligibility for the Medicaid program; the Division of Health Care Financing and Policy, which Mr. Liveratti is representing, handles all Medicaid services; and, the Mental Health and Disability Services Division, which Mr. Luke is representing, provides services to mentally challenged children. The divisions are attempting to coordinate their efforts to ensure the families who need these programs are provided for. The parental responsibility program has been effect

for about 10 years and this workshop is being held to determine if it should be modified and/or updated.

Mr. Luke commented the state staff also have some trouble understanding how the parental responsibility program works at times. He asked for input from the community as to how the information could be made more user-friendly. Ms. Ford suggested a brochure or other literature be created to help people better understand the program.

A concerned parent, whose identity could not be heard on the record, stated she has two children with autism and understands the Katie Beckett program and parental financial obligation for the coverage is being discussed. Her family has been going through the process for over two years. They have gone through different agencies and has received support from them. However, changes need to be made to the policies for parental financial obligation. She was told when the parent's obligation is reviewed the number of children is taken into consideration. However, there are several things not provided by Medicaid that she must pay out of pocket, in addition to the parental obligation amount. Her case manager was able to qualify one of her children for additional funds to help out with the medical and support services bills. While she and her husband make a good living, with the medical expenses they pay out each month, at least half of their earnings go to these expenses. They take their responsibility to their children seriously and are grateful to these programs that provide assistance to their family. Their insurance costs about \$1700 per month and their insurance company does not cover autism, but will cover other health issues, so Medicaid is their secondary insurance for their children. She believes the insurance premium and non-covered monthly medical expenses should be taken into consideration when considering parental financial responsibility. The number of children in the home with disabilities should be considered along with any other extenuating circumstances the family may have. Most families are attempting to raise their disabled child(ren) to be productive citizens with their own life and using these programs to help them along the way.

Ms. Bostic read a general statement about her family and their problems with the Katie Beckett and Medicaid Programs into the record, which is part of the permanent meeting record. She said her statement does not directly address the parental financial responsibility program, she does take her responsibility to her children very seriously and she advocates for her son's well-being. Each child is an individual and while one program works for one child, it may not work for another. Ms. Bostic believes their individuality gets lost in these programs, which is instrumental in their care. Ms. Ford commented the different agencies were present to hear concerns about services and other provisions for a disabled child's care, not just the parental financial responsibility.

Jon Sasser, Washoe Legal Services, observed some people at the meeting have been unnecessarily alarmed by this meeting. His understanding is the Welfare Division is not considering added a parental responsibility component to any of the Medicaid programs which do not have one. Mr. Liveratti stated it is not being added because parental income is already evaluated when Social Security Income (SSI) is considered and will not be considered for these Medicaid assistance programs. Mr. Sasser stated some children who are disabled and receive Medicaid incur some cost of care while for other categories of children there is none. He commented the division is not planning on adding any additional costs to the program. He also stated he believes the motivation for this hearing is not to increase the portion a parent pays for Medicaid coverage, but to see if it may be too high and causing hardships. He hopes this portion of his testimony will alleviate the concerns of those parents in attendance.

Mr. Sasser suggested a new category of deductions for these families of out of pocket medical expenses by using either a percentage of these expenses or as a credit against their parental financial responsibility payment. He asked for the fiscal impact on those not receiving services and other ways a change would impact the system. Ms. Ford thanked Mr. Sasser for clarifying the reason for the meeting. She stated the meeting is not to announce an increase or broaden parental financial responsibility, but to update it to make it more realistic for today's families as the world has changed over the last decade.

Mr. Ulmer commented the worksheet is self-explanatory, but the question was put to the attendees of how to make it easier to understand. A suggestion was made to make a pamphlet available. When a worker came to his home to see if his family would qualify for the Katie Beckett program, the parental financial responsibility was explained to them based on income. But when they were accepted into the program he was told he had no parental financial responsibility after several attempts to contact someone to find out the obligation amount. A few weeks later a notice was received stating paperwork was not received and the case would be closed if it was not submitted timely. He suggested instead of spending the funds to make the pamphlet, the money, time and effort should be spent properly educating staff about how the program works. He received three different stories regarding his case and believes agency staff is as confused as he is about the parental obligation for this program. Ms. Buck stated eligibility for assistance programs is very complicated due to federal and state regulations. Ms. Ford suggested he show his notices to Ms. Stenson to clarify his situation. He stated the program is still very confusing. Even though he submitted the large amount of information requested and was still given conflicting information regarding the program.

Ms. Ford clarified the parental financial responsibility is separate and apart from a child's eligibility for Medicaid, it does not affect the child's Medicaid one way or the other.

Mr. Ulmer asked if the parental responsibility worksheet needs to be filled out every year, as he is self-employed and his income fluctuates. Ms. Ford replied an annual re-evaluation of parental responsibility is done to review each case. If a family's income changes during the year and their parental financial responsibility is too high, she encouraged them to contact their caseworker to have them re-evaluate the case. She also stated a "true-up" is done between the Medicaid program and the parental financial responsibility and if the family paid more into the program than was used in services, the remaining amount is refunded to them. If the amount is more than what was paid in, the families are not billed for any excess amounts.

Suzanne Hurley stated she now has a better understanding of what is being asked for at this meeting and it would have been more informative to her to know exactly what the meeting was going to about so she would have time to prepare properly for it. She had concerns she was not doing something right and possibly putting her child's Medicaid at risk. She believes the child care allowance needs to be raised from \$150 as child care and respite care have dramatically increased. She would also like to have out of pocket medical expenses taken into consideration as a deduction, as it shows parental responsibility.

Ms. Ford stated comments were received in the past about parental financial responsibility being assessed retroactively as it is difficult for families to pay. She assumed removing the retroactive financial responsibility would be well-received by the families affected. Mr. Liveratti said Section 350 of the eligibility criteria for institutional Medicaid programs states medical expenses not covered by Medicaid can be deducted from the patient liability. This rule could also be applied to these Medicaid programs, if it meets with approval. A discussion regarding the how to assess an out-of pocket expense deduction and retroactive billings followed.

Lisa Erqueaga commented her child has been on the Katie Beckett Program for about sixteen years. It seems it was a well-kept secret and is glad to know more people now know it is available. While the program is a good thing, there are changes that need to be made to the parental financial responsibility and is glad to hear an open forum is being afforded to the families on the program. She suggested workshop notices include more information on what is being heard, involving the families on the program, make the workshops less formal, and have consistency in the program. She also suggested the workers have more training on the program to ensure they can properly and consistently explain the

program to applicants and parents to be more active in their child's case. The suggestion of the brochure should be taken into consideration and given to all families who apply for assistance so they know this program is available. Ms. Erqueaga would like to have an activity and expenses sheet available for parents to review at their yearly redeterminations. It is important to have the number of participants in the program who pay the parental financial responsibility available at the next meetings. The notices sent to families stating their paperwork must be sent in or they will be responsible for \$1900 should be reworded to sound less threatening. She asked to be involved in future meetings and planning for any changes to this program due to the fact she has been a participant in the program for a long time.

Tina Gerber-Winn, Chief of Continuum of Care for Medicaid, said the processes for these programs is somewhat confusing. She explained the Welfare Division handles one part of eligibility and Medicaid handles the second part, which is screening for the level of care and explains how to access services. It sounds like staff from both agencies need to do a better job explaining the program's services and requirements. She also likes the brochure idea on the parental financial liability and the eligibility and access to services process. It is important for parents to understand how much they need to do to be eligible for the Katie Beckett Program and the benefits. If services needed are not available under Medicaid's state plan, it may not be feasible for a family to have this coverage. A better job needs to be done explaining the amount of bureaucracy in becoming eligible for the program. She appreciates all the comments voiced at this workshop and better understands the problems of the families. Ms. Ford said the different state services available to disabled children should be included in a brochure so parents get real information about how to get services for disabled children.

Ms. Bostic suggested clarifying what services are covered for their disabled child, a mission statement and background on Ms. Beckett to show she is a real person. She feels it is very important to include this information so parents can plan accordingly for their child's needs. People seem afraid to ask what is covered, do not want to take the time to ask or get different responses from the state and to clarify covered services would relieve a great deal of stress from the families. She has met many people who have never heard of the program or know what it includes.

Mr. Liveratti explained Katie Beckett is a category of Medicaid coverage and not a special program with special services. A person who is eligible under the Katie Beckett program receives the same services as a person receiving Medicaid under any other category. The only difference between the Katie Beckett category and the institutional care program is the child is taken care of in the home, as they receive better care there. The services are no different for any

Medicaid category. A Medicaid Service Guide will be included in the mailing for the next workshop. It lists most of the services provided through the Medicaid Program. Ms. Ford said before the Katie Beckett program came into existence, if a parent wanted to care for their disabled child in the home, parental income was included in the eligibility criteria, which meant the child was not eligible for Medicaid and children were forced into institutions to get Medicaid coverage. So, the Katie Beckett eligibility category was founded to keep children in the home with their families and provide necessary Medicaid coverage for them.

Ms. Matrone encouraged more training for eligibility workers, as opposed to developing a brochure for families. The eligibility workers do not seem to understand the eligibility criteria and are unable to provide equal access to the program statewide. The training would be more advantageous than developing another brochure for people to read. Ms. Ford explained to be eligible for the Katie Beckett Program a child must be eligible for a nursing level of care and be cared for at home instead. If the child is not eligible for that level of care, they will not be eligible for this Medicaid category. Eric DeWitt-Smith explained there are many levels of care eligible for the Katie Beckett Medicaid category and it must be shown the disabled child required care on an institutional level.

Mary Liveratti thanked the parents for coming forward to share their stories and concerns. When she; Mike Willden, Director of the Department of Human Resources; and, Dave Luke, MHDS, visited families, they heard many compelling stories about the hardships faced by families to keep their special-needs children out of an institution. She encouraged everyone to give information to them so a broad-range of input can be considered. Written comments are welcome to be sent via letter or e-mail if someone is not comfortable appearing in person. She thanked the parents again for participating. She also thanked the different divisions for explaining how the programs work and making them easier to understand. Ms. Ford believes there are still many people who would like to continue the dialogue begun at this workshop and will set up more informal workshops in the north and south to share information and come up with policy good for everyone. She encouraged anyone interested to provide their name and address to the secretaries so they can be included on the public meeting mailing list.

II. GENERAL PUBLIC COMMENTS:

None received.

Ms. Ford thanked everyone for their participation and attending this public workshop. Hearing no further comments, she closed the public hearing at 10:33 a.m.